



STATE OF WASHINGTON
WASHINGTON STATE BOARD OF HEALTH
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Summary of Planned Work

Genetics Task Force

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Overview

The state biennial operating budget for the 2001-2003 biennium requires the Board to convene a "...broad based task force to review the available information on the potential risks and benefits to public and personal health and safety, and to individual privacy, of emerging technologies involving DNA. The task force must consider information provided to it on

- a) incidence of discriminatory actions based upon genetic information
- b) strategies to safeguard civil rights and privacy related to genetic information
- c) remedies to compensate individuals for inappropriate use of the genetic information, and
- d) incentives for further research and development on the use of DNA to promote public health, safety and welfare.

We must report our findings and any recommendations to appropriate legislative committees by October 2002.

Selecting Task Force Members

By November 15, the Board will name a broad based task force, reflective of the primary genetics issues it must consider under the terms of the proviso. The task force will include representation from:

- (1) local public health;
- (2) state public health;
- (3) public purchasers of medical care;
- (4) private purchasers of medical care;
- (5) health insurance carriers;
- (6) primary care physicians;
- (7) pathologists or laboratory medicine;
- (8) genetics counselors;
- (9) hospitals;
- (10) genetics ethicists;
- (11) institutional review boards;
- (12) research geneticists;
- (13) trial attorneys;
- (14) medical research institutions;
- (15) civil rights advocates;
- (16) privacy advocates;
- (17) citizens who have undergone genetic testing;
- (18) parents whose children have been helped by genetic testing;
- (19) the biotechnology industry; and
- (20) an expert in privacy laws and rules, especially as required under HIPAA.

To assure maximum continuity in expert opinion available to the Board, members will be selected first from several already existing SBOH/DOH genetics issues committees.

These committees include the Newborn Screening Advisory Committee, the Pre-natal Screening Advisory Committee and the Department of Health's Genetics Services Advisory Committee. To the extent broader membership is required, the Board will next

solicit members from relevant professional societies or associations as indicated below. The table below indicates the candidates or nominating organization for Task Force membership using this process:

Task Force Position	Possible Member	Current Affiliation(s)
(1) Local public health;	Vickie Kirkpatrick	Newborn Screening Advisory Committee, WSALPHO
(2) State public health;	Maxine Hayes	State Health Officer, Newborn Screening Advisory Committee
(3) Public purchasers of medical care;	Ree Sailors	Governor's Health Policy Advisor, Newborn Screening Advisory Committee
(4) Private purchasers of medical care;		Association of Washington Business
(5) Health insurance carriers;	Margaret Stanley	Regence Blue Shield, Association of Washington Health Plans, Newborn Screening Committee
(6) Primary care physicians;	Tom Curry	WSMA, Prenatal Screening Advisory Committee
(7) Pathologists or laboratory medicine;	Julie Sanford Hanna	President, Genetics Advisory Committee and Sacred Heart Medical Center
(8) Genetics counselors;		National Society of Genetic Counselors
(9) Hospitals;	Brenda Suiter	WSHA, Newborn Screening Advisory Committee
(10) Genetics ethicists;		UW School of Medical History and Ethics
(11) Institutional review boards;		UW Investigation Review Board or DOH-DSHS Joint IRB
(12) Research geneticists;		American Society of Human Genetics
(13) Trial attorneys;		Washington State Trial Lawyers Association
(14) Medical research institutions;	<i>Ian Glass or Ron Scott</i>	Newborn Screening Advisory Committee, Children's Hospital and UW
(15) Civil rights advocates;		American Civil Liberties

		Union
(16) Privacy advocates;		American Civil Liberties Union
(17) Citizens who have undergone genetic testing;		Alliance of Genetics Support Groups
(18) Parents whose children have been helped by genetic testing;	Michael Gray	Newborn Screening Advisory Committee
(19) The biotechnology industry; and		Washington Biotechnology Association
(20) An expert in privacy laws and rules, especially as required under HIPAA.	Vickie Hohner	DOH, HIPAA and Agency Privacy Coordinator

Other interested parties, including legislators, state agency and interested citizens or private sector representatives wishing to attend meetings or be kept informed of the Task Force's work will be encouraged to do so through the Board's web page or by attending meetings.

Task Force Staffing and Technical Assistance

Board staff will manage logistical arrangements for the Task Force, including meeting locations, mailing lists, agenda distribution etc. Board staff is discussing the possibility that research, technical staffing assistance and report preparation be provided by the University of Washington Public Health Genetics Program. It is anticipated that total costs for the Task Force and its staffing will be absorbed with funds appropriated to the Board, including those associated with the proviso.

Scope of Work

The scope of the Task Force's considerations will be limited to the objectives set forth in the legislative proviso centering on privacy of genetic information as collected, stored and shared within the public health and medical care systems, including insurance, and the sharing of this information with employers or potential employers and life insurance underwriters as balanced against the risk of harm to scientific research and development that can benefit public health, safety and welfare. It is suggested that the Task Force's exploration of "incentives for research and development" exclude stem cell research and cloning, and focus on potentials to advance knowledge and improve practice in the context of privacy and discrimination concerns and potential regulations.

Schedule of Meetings

The suggested schedule for the Task Force is six, day long meetings. It is anticipated that the first meeting will be on January 3, 2002 in Olympia. The April 2002 meeting will be held at the Henry Art Gallery on the Campus of the University of Washington to coincide with the opening that month of exhibits and other activities designed to engage the public at large in thought, reflection and dialogue on genetics issues. (Please see the attached

draft explanation and preliminary schedule of events attached.) Other meetings will be held in the Seattle/Olympia area.

To complete the Task Force's work in time to meet the legislatively imposed schedule, it is suggested that the meetings occur in the following months, as follows:

Task	Timeline
The Board Solicits nominations for Task Force Membership	October 2001
The Board Appoints Task Force Members	November 2001
Conduct Initial Task Force Meeting to hear from Prime Legislative Actors Pro and Con; Review the Findings of the Recent Joint Select Committee on DNA Identification; Obtain Background on the Charge to the Task Force and Related Processes; and Become Familiar with Current Law and Official Policy in Washington on Regulating Genetics Privacy and Discrimination, Including Relevant Research Regulations	January 3, 2002 (Olympia)
Conduct Task Force Meeting to Receive Evidence of Violations of Genetics Privacy Principles and/or Genetics Based Discrimination; Review and Discuss Genetics Privacy and Discrimination Problems and Policies from Other States; Discuss Options to Address Any Problems	Mid March 2002
Conduct Task Force Meeting to Review Information on Bio-tech Industry Research and Development Plans and on Desirable Incentives to Stimulate Genetics Research and Development; Receive Public Comment on Options to Address Any Privacy or Discrimination Problems Identified; Discuss and Attempt to Settle Upon Options and Possible Recommendations on Privacy and Discrimination	Late April 2002 (Henry Art Gallery at UW in Seattle)
Conduct Task Force Meeting to Review Draft Task Force Report; Conduct Further Task Force Discussion of Possible Recommendations if Needed; and Approve Report, if Possible	June 2002
Conduct Task Force Meeting to Approve Final Task Force Report and any Recommendations	September 2002
Presentation of Final Report to the State Board of Health and to the Legislature (at the October Board meeting)	October 2002